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ABSTRACT

This publication aims to help families better access services for their disabled children and organize their records for maximum efficiency. The suggestions are designed to help families develop personalized local directories of services for their individualized needs. The four chapters have the following titles: "Guide to Parent Groups," "Guide to Community Services," "Rural Families," and "Record Keeping." (PB)

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A PARENT'S GUIDE

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TO ACCESSING PARENT GROUPS, COMMUNITY SERVICES, AND TO KEEPING RECORDS

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In Memory of George Ziegler

This booklet is dedicated:

To all families who are living with a child with a disability,

To the professionals who help our children to grow and to learn,

To our children with disabilities who have so much to learn from us and so much to teach us,

And especially to Martha Ziegler who has worked tirelessly for the families, the children, and the teachers to establish a place for all of us in our society.

INTRODUCTION

Families who have a child with a disability need information about their child's disability, about services available which can be helpful to their child, about federal and state laws and policies which affect their child, about support for their family when needed, and, as in all other families, how to live together comfortably while meeting everyone's needs. This is a large order!

NICHCY receives literally thousands of letters each year from families asking questions about disabilities, about school, about therapy, about recreation programs, about laws, about Individualized Education Plans (IEPs), and about other families in similar situations. In answering these questions, it has become apparent that what parents need is a course in the PROCESS of finding such information. When people know how to access the resources, they have the ability to explore their options. It is the self-confidence of knowing how to find the help needed, and the knowledge that there is still another "door to knock on" that keeps families going.

The chapters in this publication were written as a guide to the "how" of accessing services and organizing records for maximum efficiency. It was written by parents and friends of children with handicapping conditions, who want to share with you the lessons they have learned. Families who use these suggestions should be able to develop personalized local directories of services for their individualized needs. The materials are written to cover any disability, to discuss options in any state and to be general enough to be useful to families of children at any age, stage, or level of need. Attached to this publication is a **State Resource Sheet** for your state and a list of **Toll Free Numbers**. This resource sheet is updated annually; you should request a new copy if yours is more than one year old.

Of course, NICHCY is still available to answer your questions, provide additional referrals and to assist you whenever possible. Please contact us as needed. You may write to NICHCY at this address: NICHCY, P.O. Box 1492, Washington, D.C. 20013. Or you may call NICHCY at this toll free number: 1-800-999-5599.

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CHAPTER 1

GUIDE TO PARENT GROUPS

Q: WHAT ARE PARENT GROUPS?

A: Parent groups are, very basically, a group of parents, or primary caretakers, all of whom are concerned with disability issues. Parent groups vary on the basis of what binds them together. There are groups of parents all of whose children have the same disability, such as cerebral palsy or spina bifida; there are groups of parents whose children all attend the same school or programs; and there are parents who have formed a group based on the same needs, such as advocacy training or learning sign language. In addition, there are some groups whose members needs are more diverse but who all live in the same geographic area.

Historically, parent organizations have played an important role in shaping the lives of children with disabilities and their families. Groups of parents are formed to help their members collect information, provide emotional support, and form a politically active unit. They existed before the passage of federal laws mandating special education services and continue today in their function of organizing families to actively participate in the decision making processes which determine the direction services will take for their children. The strength of parent organizations comes from bringing together families who are facing similar decisions and living situations. Parents, in groups, can work together to collect needed information and can find the rejuvenation they need to carry out their responsibilities in providing for their children.

Parents of a child with a disability have something in common with other parents of a child with a disability. When a parent realizes that other parents have similar experiences and difficulties, fears and hopes, a bond is formed. Often this connection between people overcomes the economic, social, educational, religious and geographic differences that exist. It is helpful for parents who may feel alone facing the realities of raising a child with a disability to get together with other parents "who have been there". Together they experience the comradery of similar and challenging parenting.

Q: ARE YOU THE ONLY FAMILY LIKE THIS?

A: No! You are not!

There is great benefit in learning that there are other families going through the same situations. Families join parent groups to end the sense of isolation their unique situation can create. Parents have empathy for each other's needs, successes and sorrows. Groups also serve other important needs and offer several advantages.

Parent groups can provide information on services, programs, resources and everyday tips on how to make life run smoother. They have experience with various systems which provide services and information. This information is invaluable for "new families" who have just learned of their child's disability and is available to families as their needs change through the years. These groups can provide the opportunity for families to come together to create a new belief in themselves, in their ability to live this new life, and to continue seeking solutions to ongoing difficulties effectively and competently. Most importantly, they form a united voice like any other special interest group.

Q: WHAT SORT OF HELP CAN PARENTS REALLY OFFER EACH OTHER?

A: Parents can be open about their fears and concerns, they can offer each other practical assistance and, through these processes, they can renew their spirit, determination and enthusiasm for life.

Throughout history people have joined together to face difficulties. Certainly families of children with disabilities have also benefited from this philosophy. As a group, families can invite speakers who are experts on a wide variety of topics to speak at their meetings; they can invite school administrators and community leaders to address their concerns; they can speak to elected officials as a united voice; they can produce a newsletter concerning local services, events, school policy, state policy or even classified ads for specialized equipment. These families are their own experts on local services, medical facilities, schools and community services, as well as the daily coping techniques for keeping families together.

Basically, families in untypical situations may find traditional sources of help unable to understand their particular needs and unable to help them problem-solve. Being able to discuss concerns with others in the same situation can bring about solutions and is often just the support families need.

Q: WHAT KINDS OF GROUPS ARE THERE?

A: There are groups made up exclusively of families, such as Parent-To-Parent or Pilot Parents, and other groups which are a mix of parents and professionals working in the disability field. Groups such as the Association for Retarded Citizens (ARC) or the Spina Bifida Association (SBA) are joined by anyone concerned with disability issues. Many parents belong to such organizations too.

Some groups have local, state, regional and/or national offices with sizable membership lists. Some groups may have as few as three members, but this can still be a workable group. It is not size that determines the effectiveness. There are groups which are entirely run by volunteers and have no income other than possible membership dues. There are local groups which have applied for and have received federal funding or state funding to help pay for

staff time, printing, mailing, and maintaining a post office box or office. There are large organizations with a full staff of paid workers who have budgets which allow for national publications and annual conferences. It is important to remember that all groups play an important role in the areas of family information, support and the presentation of a collective voice.

Q: SHOULD YOU JOIN ONE OF THESE GROUPS?

A: When considering membership in one or more parent groups it is helpful to define your personal needs. Are you looking for moral support or advocacy training? Do you need a course in sign language or a play group for your three-year-old who is blind? The answer may mean that you are looking for either a group which provides for a variety of needs, or perhaps you need to consider joining several groups. Maybe joining the local Association for Retarded Citizens would provide the up-to-date information that you need on respite care, summer camps, school programs and developments in the field of special education, but you are also going to join the preschool parent group which gets parents together to discuss the very class your child is currently in, and which holds birthday parties for each of the children. Membership in some local groups automatically places your name on the mailing list for the national newsletter. For example, joining the local Association for Children and Adults with Learning Disabilities will provide you with a subscription to the national newsletter. Dues or fees vary for different groups, as do meeting places, speakers, size of the meetings, frequency of meetings, and scope of topics discussed. In the process of exploring parent support organizations, remember that you can always attend one or two meetings before making a commitment to join.

Q: WHAT IS PARENT-TO-PARENT?

A: There are several names for this organization: some are called Parent-To-Parent, some are Pilot Parents, some are Parents-Helping-Parents, and similar titles. Under a variety of names this is a peer support program in which parents of children with handicaps provide information and support on a one-to-one basis with parents of newly diagnosed youngsters. A "new" parent contacts the program to request help. The director then matches parents on the basis of type of disabling condition and or other appropriate variables.

The parents who form the experienced-parent half of this match receive training to ensure their ability to handle emotional as well as informational requests. They are taught techniques to facilitate the adjustment of new parents to their child who has, or is at risk for, a handicapping condition by providing emotional support and practical information. Although the experienced and new parent may have children who are similarly disabled, the relationship is designed not as a bonding of persons who have similar problems, but rather to assist the new parent with problems the helper has already encountered. Initial contacts may take place in the hospital shortly after a child is born, if a

referral process is well established, or later when a new parent is referred to the program or calls with a request for help. Calls are informal and take place only if the new parent requests assistance.

Q: WHERE DO YOU FIND SUCH A GROUP?

A: These programs are in existence across the country and in Canada. In some states there are state offices; other states are not centrally organized. There is no national Parent-To-Parent office. This may cause some inconvenience in locating services in your area.

To find the contact in your part of the country, start by checking the attached State Resource Sheet for a state listing. That office can direct your request so a pilot or helping parent can be located for you. If there is no state office, there are several alternatives. One is to phone the social services division of the nearest pediatric hospital. Another is to contact NICHCY, and we will be glad to find the people who can help in your state. Phone toll free 1-800-999-5599 and leave your message on our recorder. Other state offices specializing in disability issues are also excellent resources for referral and information. If your state has a federally funded parent training center (listed on the State Resource Sheet) they may be helpful. The state Association for Retarded Citizens (ARC) offices, Easter Seals centers, or other well-organized groups can provide you with information you may need whether or not your child fits the specific diagnosis that these groups normally service.

Q: HOW DO YOU START A PARENT-TO-PARENT GROUP?

A: If your area has no Parent-To-Parent group, you may wish to start one. Finding and contacting the nearest Parent-To-Parent group for information on their program, their brochures, training programs, forms, etc. can be extremely helpful in getting your group started. They may have a "Guide for Developing a Parent-To-Parent Support Program" that you can obtain. The following list offers steps to help get started. The process is outlined and can be modified to suit your needs. (This material was adapted only slightly from a product developed by Florida Parent-To-Parent on the issue of beginning a Parent-To-Parent group.)

GETTING STARTED

1. ESTABLISH a core group or steering committee.

   A Parent-To-Parent program may be established by any number of people, anywhere. A parent of a special needs child, realizing the need for such a program in his or her community, may advocate for its development. The staff member of a service agency, aware of the value of the program to parents of special needs children, may advocate among parents to organize a program. Or perhaps a group of parents may band together with professionals to establish a program.

2. DETERMINE leadership. (Appoint or elect a Chairperson, secretary, public relations chairperson, etc.)

3. INVITE a local professional to be your resource person.

4. LEARN the specifics of Parent-To-Parent. If your state has a training manual, read the manual carefully and become familiar with the program. (If no one in your state has one, contact NICHCY and we'll put you in touch with a near-by group.)

5. PLAN a meeting to explain your Parent-To-Parent group goals to local service providers and parents to ascertain whether or not such a program is needed.

6. SOLICIT support of agencies for a meeting place, printing, postage, consultations, telephone, etc.

7. RECRUIT parents with guidance by professionals who know them well. Remember, you will not be able to obtain any names and addresses of persons you do not already know (due to confidentiality issues). These parents will need a letter sent through the service providers telling them about Parent-To-Parent and asking them to contact you or to attend the introductory meeting.

8. SET UP an introductory meeting for prospective Parent-To-Parent parents. Explain Parent-To-Parent, discuss plans for training, commitment. A screening interview tool or self-assessment checklist should be available for parents if they are unsure.

9. SET UP training sessions, preferably at a time when fathers can attend also. Six sessions of two hours each is one suggested format; however, training should be adapted to fit the needs of parents; e.g., one Saturday training session with follow-up inservices. Consider dates and location (it is a good idea to start two weeks from the introductory meeting). It is suggested that you provide refreshments and sitters in an effort to get both parents to attend. Invite local service providers and professionals to conduct some training sessions.

10. TRAINING SESSIONS The general divisions are as follows:

    1. Orientation
    2. Developmental Disabilities/Special Needs
    3. Peer Counseling Skills
    4. Parent-To-Parent Support
    5. Resources
    6. Referral Process and Community Outreach

11. LOCATE a local referral phone number and Referral Coordinator. Preferably an 8:00 a.m. - 5:00 p.m., five days a week number. A 24-hour service may not be necessary at first but may be a consideration in the future.

12. OBTAIN publicity.

    Brochures: To medical doctors, hospitals, advocacy groups, mental retardation centers, schools, chaplains, public health nurses, clergy, and others as appropriate.

    Speakers: Select parents to talk about Parent-To-Parent to nurses inservice and medical section meetings, Parent Teacher Associations, ministerial association, and other groups as appropriate.

    Media: After professionals are contacted, get coverage from radio, TV and newspapers.

13. MONITOR the efficiency of the program.

14. ESTABLISH continuity.

    Monthly meetings may be designed to be parent support meetings for supporting parents, referred parents and/or parents in the community who are interested in a parent support program.

    The services of a Parent-To-Parent support group can include the following in addition to providing one-to-one support:

    A. A parent newsletter.

    B. Monthly social gatherings.

C. Information packets (about disabilities, organizations and services available).

D. Workshops for professionals and students on communicating with people who have handicaps and their families.

E. A 24-hour answering service.

F. Speakers for groups and classrooms.

CHAPTER 2

GUIDE TO COMMUNITY SERVICES

Q: WHAT ARE COMMUNITY SERVICES?

A: Public and private organizations in your community which provide health, education and other human services to the people living in your area are called Community Services. Some of these public programs are administered by the federal government, and others by county or city governments. Such organizations include your state's Department of Education, Social Security Office, Health Department, Parks Department, Recreation Centers, Department of Housing, and the Protection and Advocacy Agency. These are all public agencies. These programs and services are funded by tax dollars, and therefore do not charge the people who use their services. The State Resource Sheet at the end of this package lists the key state public agencies concerned with children and youth with handicaps. These state offices should be able to refer you to the local service providers in your community.

Private organizations also provide needed services. These private agencies may charge a fee for their services (sometimes on a sliding scale based on family income), or they may be funded to offer their services free of charge. Such private organizations concerned with disability issues include the Easter Seal Society, March of Dimes, Lions Club, Shriners, and Masons. Private organizations are also listed on the State Resource Sheet at the end of this package. Again, your state's office of Health or Welfare should be able to refer you to local offices in your community or provide you with information on local services.

Q: WHAT DO COMMUNITY SERVICES PROVIDE?

A: Community services can provide special education services for children or instruction for special education professionals. They can provide speech therapy, physical therapy, occupational therapy, recreation, modified housing, adaptive equipment such as wheelchairs or hearing aids, medical care, or counseling for the entire family. Many of these services are either free of charge, based on family income, or covered by personal insurance. Private services may vary in price and, like all purchases, their affordability will have to be judged individually. It is always good to check to see if scholarships are available.

Q: HOW DO YOU LOCATE SERVICES IN YOUR COMMUNITY?

A: Locating services and programs can be a challenging task the first few times you try it. As with many tasks, practice helps. There are several general guidelines to this process. Ask yourself several key questions before you begin.

1. What does your child need?

2. What does your family need?

3. What are your questions? (Before you call you should formulate specific questions for obtaining the information you need.)

The next step is to formulate the specific questions you will ask the agency when you reach it. It might be useful to write a list of your questions with spaces for the answers in a notebook. This is to help you keep all your information organized. Be sure to include a space for the name of the person to whom you speak, the name of the agency and the phone number. Frequently, callers are transferred or referred to other offices and the name of the contact person and phone number is not the one you first dialed. To avoid confusion and future repetition of calls, keep track of all contacts, even those who were not helpful. A contact of no help this week may be exactly who you need to talk to next year. Keep this in mind as you continue to organize your files and keep your records in good order. The notes and comments you have on the conversations held, even with people who are not helpful, will most likely be useful in the future also, although it may not always seem so.

Q: WHAT DOES A SAMPLE RECORD LOOK LIKE?

A: A sample record might look like the following:

Date: _____ Agency called: _____

Phone Number: _____ Person spoken to: _____

Question: _____

_____

_____

Answer: _____

_____

_____

_____

Comments: (Include here information on what this agency and/or person can do, how it can be done, and your personal impressions of the conversation.)

_____

_____

_____

By keeping good records of your calls and contacts you can better formulate your questions and keep track of the advice you are given. It also helps you create a local directory of resources for your child. You are developing just the resources you must have in order to respond to future questions.

Q: HOW DO YOU FIND THESE PHONE NUMBERS?

A: All phone books have some type of table of contents, sometimes called a Customer Guide, on the first pages. Generally there is a section called Community Service Numbers, and within this section is a subdivision called Human Services Information and Referral. This is a good place to start for community contacts.

SCHOOL INFORMATION: If your questions are related to school, then call either the local school to ask for referrals, or phone the special education office of the public school system. The phone book listing for the schools is found under the name of the county or city which has listings for specific administrative offices. This is where you should begin your search for school information.

Q: WHAT SHOULD YOU DO WHEN YOU FIND THE PERSON YOU NEED TO CONTACT?

A: When you contact the person you are looking for, be sure to have your list of questions ready and keep track of the information you collect. THIS CANNOT BE OVEREMPHASIZED!

You will need to know who was helpful, who performs what services in your area and how to access those services, and others you may still need to contact.

Your local public library may be another resource. The reference section of libraries may include vertical files of local resources. Talk to the reference librarian and ask if there is information on local disability groups, specialized clinics or if there are any books about disability issues. Check the publication date of these books; anything written several years ago may have out-of-date information and be somewhat misleading. For instance, The Education for All Handicapped Children Act, Public Law 94-142, was passed in 1975, while the legislation for serving infants and toddlers was enacted in 1986. Much of the information in older books may still be valuable, but some of the information in these books may be dated in terms of legislation and terminology.

MEDICAL INFORMATION: Families in need of medically related information may find it useful to contact the social services office of the local hospital. The staff of the social services office frequently keep a comprehensive listing of local service providers, such as firms which supply adaptive equipment, medical supplies for the home, visiting or private duty nurses and aides, respite care providers and other necessary services for both long and short-term needs. They may also be able to help with medical insurance questions. While services vary from hospital to hospital, this is a resource which should not be overlooked.

In general, once you locate a good resource, that is, someone who seems both current and interested in disability issues, ask for referrals to other local resources. This is a tightly knit field and people tend to know one another, even in major metropolitan areas.

Q: WHAT DO YOU DO WHEN YOU CANNOT REACH THE PEOPLE OR GET THE INFORMATION YOU NEED?

A: Sometimes, even after you've located the correct number, you can't get the answers to your questions. This can be very frustrating. THE BEST ADVICE IS TO KEEP ON TRYING.

Bring a magazine with you to the phone; you may spend some time on hold and having something to look at will ease the frustration. If you have had no success, there is another route.

Q: WHAT DO YOU DO IF YOU HAVE HAD NO SUCCESS AND ARE DESPERATE?

A: After all other resources have been exhausted, or if you already know the name and number of the appropriate resource but have found it impossible to reach this person or persons, you might try the local office of your elected representative.

Elected officials at the local or state level have information people on staff to answer questions from their constituency. However, you need to have your facts together before they can help you.

- First, they will need to know your SPECIFIC QUESTION(S).
- You must be able to tell them how often you tried to obtain the information and failed.
- You must be able to tell them who you spoke to and their willingness to help, and why the information was not adequate or forthcoming.

It would probably be best to choose only one or two questions from your list. Be sure to ask the congressional staff person for names and phone numbers of the people from whom he/she received the information he/she is passing on to you.

REMEMBER: IT IS MOST IMPORTANT THAT YOU TRY TO LOCATE THE INFORMATION YOURSELF FIRST.

The staff of an elected official's office can be extremely helpful, but it is wise to save them for occasions when their expertise is really needed or when an issue is extremely important or crucial. After all, it is not a good policy to wear out

one's welcome with smaller, less crucial issues.

Some states have information and referral lines that are toll-free. Such agencies provide information about essential service providers in the communities of your state. Some of these agencies may be public and others private. Check the attached State Resource Sheet and the attached Toll-Free Numbers List for applicable contacts for your area.

CHAPTER 3

RURAL FAMILIES

Q: HOW DO RURAL FAMILIES LEARN ABOUT SERVICES?

A: Services for children who are handicapped are mandated in all states. The difficulty for some families, especially those living in rural areas, is access to these services. Obviously, it is financially difficult for an educational system to provide a service for only one or two children, or to arrange groups when there just aren't enough children to form a group. Thus even though services are mandated, they are sometimes unavailable.

On the other hand, low incidence is not a valid reason to deny the services exceptional students need. In rural areas, getting help is often difficult, but there are groups who address this concern.

Q: ARE THERE NATIONAL ORGANIZATIONS CONCERNED WITH RURAL CHILDREN IN NEED OF SPECIAL EDUCATION?

A: YES!

ACRES, the American Council on Rural Special Education, is an organization concerned with the problems of rural students needing special education and their families. ACRES works to do the following:

1) Improve services to individuals with disabilities and agencies serving such persons,

2) Initiate and support interagency afforts to increase educational opportunities for rural handicapped and gifted students,

3) Serve as an advocate for rural special education at the federal, state, regional, and local levels, and

4) Develop and implement a system for forecasting the future of rural special education and to plan creative service delivery alternatives.

In 1984, ACRES developed task forces which work on specific issues according to the interests and fields of expertise of the members involved. Among these was the ACRES Rural Family-Professional Partnerships Task Force. Two of its goals are to promote better communication and cooperation among parents and professionals and to identify resources for rural families.

ACRES also hosts an annual national conference, implements an electronic "Rural Bulletin Board," publishes a quarterly rural special education newsletter, and offers rural job services and other benefits.

For further information write: ACRES, National Rural Development Institute, Western Washington University, Bellingham, WA 98225; (206) 676-3576. Each state has a staff person concerned with rural issues. This contact is listed on the attached State Resource Sheet.

In starting a search for services, support groups, local medical services etc., you might start by contacting ACRES and your state's rural representative, as listed on the State Resource Sheet.

☆ ☆

Rural families who have children with disabilities frequently encounter concerns that families living in more populated areas do not have. Research studies conducted by the National Rural Project and the American Council on Rural Special Education (ACRES) from 1978 to 1984 identified a number of factors which frequently inhibit interaction between families of children with disabilities and professionals in rural areas. The following article discusses these factors.

Successful Rural Family-Professional Relationships

by Doris Helge, PH.D.
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American Council on Rural Special Education (ACRES)
Western Washingon University, Bellingham, Washington

(This article is used by permission from the author and was excerpted from the Rural Special Education Quarterly: Vol 5, No. 3, Fall 1984, pp.4-5.)

The involvement of families in educational programs for rural students with disabilities is essential for program success. Families are resources for program follow through (particularly in summer months) and can supply new information useful to teachers and therapists. Parents and siblings, through involvement, develop more realistic expectations for childrens' achievement. Effective family communication systems increase the level of support for special education in the rural community. Typically, long term relationships are established because many rural special educators are responsible for a handicapped child for more than one year at a time. Students usually feel most comfortable when there is a close working relationship between parents and school personnel — both of whom they respect.

Problems Involved

Research studies conducted by the National Rural Project and the American Council on Rural Special Education (ACRES) during 1978-84 identified the following factors which frequently inhibit family-teacher interactions in rural areas.

Rural community mores and values are different from those of non-rural areas. Many rural family members are reluctant to become involved with schools because they feel that school personnel are authority figures.

Many rural parents are unaware of their rights and those of their children as per Public Law 94-142 requirements. Most rural communities lack family resources such as parent support groups or programs.

Vast distances between schools and homes, sometimes combined with inclement weather or impassable roads, impede family and school staff to travel. Transportation is also expensive and time consuming for rural parents who must drive long distances so that their child can participate in a quality program.

Adolescents frequently leave home at unusually early ages. Parents lack ownership/responsibility for such children.

Financial concerns are problematic because the expenses of medical attention and specialized equipment are almost insurmountable for most rural families. Hiring babysitters is often impossible.

Quality respite care is frequently unavailable, and the constant strain of caring for a disabled child can cause families to break up.

Successful Strategies

Social Ties

Rural parents are reticent to become involved with the "authority figures" of the school regarding their child's program. Thus it is essential that special educators (and administrators) establish a positive rapport with parents. It is usually easier to do this via a one-on-one contact discussion between special educators and parents regarding the strengths and weaknesses of the child's performance. It is frequently useful to precede such a discussion with a social contact. In fact, many rural districts host non-threatening social events or meetings preceded by a meal. Free babysitting is also an established part of such events in several rural districts in Arizona, and parent willingness to share valuable information with the schools and to follow up educational instruction within the home setting have dramatically increased.

Special educators who become respected community members have the most success with parents becoming actively involved with the special education program. Even itinerant staff who only visit a community once a month can express a sincere interest in community events and problems. This is especially true if they talk with the key communicators in the community.

Home visits, after sufficient rapport has been established, are invaluable. Typically, itinerant staff, rural interns, or practicum students who accept invitations to visit or stay in students' homes while traveling learn a great deal about the real strengths and stresses of the family and generate the most success for the special education program. Because of this, many districts plan mobile instructional vans traveling through isolated regions with sparse populations of low incidence handicapping conditions. Generally, this also increases the commitment of the professional.

Non-School Personnel

Discussion/support groups led by parents are much more successful than those led by professionals. Rural districts in Maine found that a public service announcement made by a parent stating that he was not affiliated with the school and would like to visit with and possibly assist other parents was particularly successful. The parent groups originally met on their own and later became an integral part of the school's feedback system.

Messages can be sent to isolated rural communities via persons who frequent such areas on a regular basis (e.g. mail carriers or utility meter readers).

School personnel should work cooperatively with other agencies who visit families or provide services to those with disabilities (e.g. county demonstration or home health agents).

Arrange meetings of parent groups with diverse foci and encourage them to share personal achievements/ideas and occasionally have joint projects. Joint advocacy projects are more effective than those of single parent groups.

Inform local physicians which parents are willing to meet with parents who are just learning that their children have disabilities. It is extremely helpful for parents newly experiencing emotions such as shock, grief and hostility to have a parent near who understands these emotions. This is a particularly effective strategy in rural areas where parents (and sometimes physicians) know which families have children with disabilities.

Educate local physicians regarding the needs of parents of disabled children and community resources that are available to them.

Family

The involvement of siblings and extended family members is an asset. This practice also frequently encourages reticent parents to become involved.

Involve families in designing unique special education strategies (e.g. rural orientation and mobility markers).

Technology

Technological devices can be as simple as a CB radio (capable of serving several families in clustered rural areas) or a telephone answering machine. Answering machines offer parents options of listening, at their convenience, to student progress reports and appeals for instructional assistance at home.

Prepared teaching materials to be taught by parents can be coordinated with television broadcasts or telecommunication systems and supplemented by mobile vans or itinerant staff visits.

Videotapes or cassette tapes can be mailed to parents for instructional use or educators for critique regarding a student's progress. Teacher visits and/or counseling via telephone, audioconferencing, or teleconferencing can be supplemental.

Encourage families to use the "Green Thumb Network" menu of CompuServe regarding potential services of County Extension Agencies. Parents with computers could take advantage of this service.

Parent/Community Communications

"Communications books, " designed by teachers, can be sent home with children on a daily or periodic basis. Such books offer advice for at home follow-up reports of progress, etc., and can be responded to by parents.

School newsletters (even a one-page mimeographed sheet) should contain articles or suggestions made by parents and a recognition that parent support is crucial for effective teaching.

☆ ☆

Q: ARE YOU THE ONLY ONE HERE ASKING THESE QUESTIONS?

A: NO! You are not.

The isolation felt by families with a disabled child can be intensified by geographic isolation. Yet, there are other families out there, even way out there, who are facing the same issues and questions.

Q: HOW DO YOU FIND THE OTHER FAMILIES?

A: Parent groups exist in all states. The NICHCY State Resource Sheet lists many in your state. These groups, as well as those more distantly located, have newsletters which can be a link with other families.

Q: HOW DO YOU FIND OTHER INFORMATION?

A: General information, state educational policy, or medical advances can be most beneficial, even if learned long distance. Questions on toilet training, adaptive equipment, technology, toys, and sibling relationships are often among the topics in newsletters published by national groups or other state groups. In most cases the newsletters will publish questions or concerns from their subscribers, so you can ask about issues you would like to see addressed. You can write and request a "pen pal" who is living in a family like yours. You can keep current on conferences and meetings in your state and perhaps arrange to attend one. It is important to go to such meetings because it is here that you become acquainted with the people in your state who effect the changes that can improve services for your community.

Nationally, there are groups of parents who have distinctive needs and who work to link parents with others like them. Parent-To-Parent is one such organization described in the chapter on parent groups. There are groups for families whose child may have a rare health condition or a specific physical characteristic, such as dwarfism, who can establish a correspondence partner. There may be several other families in your region who are also looking for someone to talk to, so it may well be worth the trouble to ask.

The information available from established disability groups can be very helpful to families. Many of these materials are free or quite inexpensive and can provide much help for both your family and your school system.

In rural areas the schools and other service providers may have little experience with children like yours. Local civic, religious, recreational, social, and transportation agencies may have never been asked the questions you are asking. This is an opportunity for you to work together with all these agencies to learn what others have done in similar situations.

Q: EVEN IF THE DISABILITY IS DIFFERENT, WILL YOU HAVE THINGS IN COMMON WITH THE OTHER PARENTS WHO HAVE CHILDREN WITH DISABILITIES?

A: YES! DEFINITELY!

While needs may vary between Maine and Georgia, betwen New Mexico and Wyoming, there are commonalities. Isolation and limited services are problems every family with a disabled child face, and that problem is frequently more intense in rural areas. Weather, politics, finances and lifestyles may vary but the needs of children are very similar. So too are there great similarities between urban and rural needs, and each can learn much from the other.

All families are concerned with their children's need for friends to play with, toys that are adapted to specific needs, curricula geared to special needs,

acceptance in the community, social life of the family, reliable childcare, stress, special diets, relationships with grandparents, and siblings and the list goes on. Families in rural areas may have developed strong systems for providing children who are removed from other children with entertainment, and they are used to having difficulty with childcare. Urban families may be more creative about integrating themselves into social groups or educating other children about acceptance of disabilities. There is much each group has to provide. The geographical differences are very real and can be the cause of insurmountable differences between service deliveries and opportunities for children with disabilities, but their families have much to offer each other. It may be of real value to join a group located far away and to stay in touch by mail and phone.

Q: HOW DO YOU LOCATE PROGRAMS AND SERVICES OUTSIDE OF YOUR AREA?

A: A good place to start is the local library. If your community does not have one, go to your high school library. However small, libraries have access to specific literature and may be helpful in ordering needed information. Talk to your librarian about a subscription to a publication or, if finances are tight, ask for a publications list of specialized periodicals and books in print on the subject of disability. Local civic groups may take an interest in funding the library to purchase one or two books to educate the community. Also, by keeping up with the state news, you may locate programs and services you would otherwise not know about.

The Congressional Representative for your area is another excellent resource. At your request as a constituent, Congressional Staff can research local and state resources for children with disabilities and provide you and the community at large with information on state laws for children and resources for rural communities. The Congressional Representative is familiar with policy makers in your county and should be able to provide helpful suggestions. If you have located other families in your congressional district concerned with special education issues, then you can present a united voice and thereby strengthen your request.

The state department of education can send information on education policy and practices in special education for your state. Being aware of the local laws is always helpful in discussing your child's needs and your expectations of both the local schools and your state's education office. The name and number for this office is on the attached State Resource Sheet.

Contact with groups throughout the state can also be useful in informing professionals of programs they can use as models to establish needed services for your child. If a class 200 miles away has successfully adapted curriculum for a child who is blind, or another school has developed a working, integrated kindergarten for all children—those who are ablebodied and those who

are disabled—then your school may want to contact them for information on how to replicate the program in your community.

REMEMBER! THE MORE INFORMATION YOU HAVE THE MORE INFORMED YOUR DECISIONS.

Q: WHY DO YOU HAVE TO DO ALL THIS YOURSELF?

A: The answer to this is painfully simple. If you are concerned with opportunities for your special needs child, then you are the most likely one to work to locate these ideas. After all, you have only one or a few children to advocate for. The school system, recreation facilities, health department, employment agency, and all the others have many more "clients" they must work for. The energy you have to devote to these concerns is stronger and more urgent than that of someone who is doing it as a job.

Q: ARE THERE PEOPLE AVAILIABLE TO HELP YOU?

A: There are many people who are available to help you. Please read the section on Community Services, contact ACRES, and contact NICHCY. The State Resource Sheet at the end of this section lists many more resources. By educating yourself and your community you are taking the first necessary step to help your child and to ensure that services will be provided to your child.

CHAPTER 4

RECORD KEEPING

Q: YOU HAVE SO MUCH TO DO AND SO MUCH PAPER TO KEEP TRACK OF, WHAT DO YOU DO?

A: One of the most practical and useful projects for parents is the formulation of a home file containing your child's medical, developmental and educational records. Keeping records of progress and activities on each child is useful for all parents, but it is especially important to document such events in the life of a child with disabilities.

Q: YOU HAVE SO MANY RECORDS, WHY DO YOU HAVE TO KEEP THEM?

A: Depending on the nature of the handicapping condition, records can accumulate quickly. Every specialist you see — medical, school, community, agency — will have plenty of questions about your child's development and past experiences. With a good record keeping system, you can answer such questions with detailed accuracy and with minimum effort on your part. As your child reaches school age, these records become even more complex. As time goes on, it is difficult to remember early details such as when your child first sat up or when he/she spoke his first words; however, with a good record keeping system, you will not need to rely on your memory.

As the school years pass, these records are an excellent indication of the areas in which progress occurred and those areas where help is needed. A comparison of gains, and stability and losses within a specific time period can provide the information needed to change an Individualized Education Plan, continue in therapy, or choose a vocation. In making all major decisions, these records will provide the overview needed to make informed judgements.

Q: HOW DO YOU KEEP YOUR RECORDS ORGANIZED?

A: In order to make the record keeping process as convenient as possible, we are dividing our comments into three areas:

1. Medical records.

   Medical records refer to both the child with the disability and the rest of the family.

2. School records.

   School records start at the beginning, as early as infant stimulation programs, and go on through the high school years.

3. Community Services records.

Although this chapter lists suggestions of the types of materials which you may want to obtain and keep for your home files, it should by no means be viewed as being all-inclusive. File whatever information and papers seem relevant to your child's development.

LET'S DISCUSS THESE DOCUMENTS IN MORE DETAIL.

1. MEDICAL RECORD KEEPING.

Many school districts require a birth certificate and proof of current immunizations before a child can be enrolled in school. These records are again requested at regular intervals during the child's school years, so you will need to keep track of this information. Be sure your home file also contains a detailed developmental history of your child from pregnancy through the current time. Included should be doctors' and hospitals' reports, medical specialists consulted (allergists, orthopedists, surgeons, etc.) and therapy reports, such as speech therapy, occupational therapy and/or physical therapy. Dental records should also be kept.

Keep a list of medications being given your child at home and at school. Include the name of this medication, dosage and times given. If the child has had any adverse reactions to any medication, include records of this too, even if this record is a note you have written to yourself as a reminder of the difficulty. You may find this medication prescribed again, and you will want to be sure to anticipate any difficulties and to inform the doctor. If the medication is discontinued, note that information as well.

2. SCHOOL RECORD KEEPING.

Keep a file for each year or part of a year your child is in school, or a school-type situation. Be sure it includes:

1. The name of the school or program.

2. The school address and phone number.

3. The names of the teachers.

4. The name of the psychologist (if any) and why there was a referral to a psychologist.

5. The names of any related service people who work with your child.

6. The name of any special education teacher (if different from other teachers).

7. The name of the Director of Special Education for your child's school, program or jurisdiction.

Two years or more from now, you'd be surprised how much you can forget about such details! You will also want to include any reports the school or program writes about your child, such as Individual Family Service Program (IFSP), Individualized Education Program (IEP), evaluations, tests, therapy reports, report cards or verbal reports. If the school writes to you about your child, or if you write to the school system about your child, keep a copy of the correspondence. If reports are developed by the school or at the school system's request, be sure to get a copy for your files.

Q: DO YOU HAVE A RIGHT TO SEE WHAT HAS BEEN WRITTEN ABOUT YOUR CHILD?

A: You have a right to have copies of any information written about your child; EVERYTHING REPORTED ABOUT YOUR CHILD IS LEGALLY AVAILABLE TO THE PARENTS OR PRIMARY CARETAKERS OF THAT CHILD. Collect all such information for your home records. If your child is in secondary school, this is especially important since many schools destroy files shortly after the student leaves the school system.

If you talk to school staff by phone or meet with them , it is always helpful to make a note to yourself about the date and subject of that conversation. File this note in your school records file. If this is an especially important conversation, it may be a good idea to follow it up with a letter restating the subject and any decisions made. A follow-up letter ensures that both parties understand the issue(s) discussed during the conversation as well as the agreed upon action(s) to be taken.

Your child's school or educational program, at any age level, will send home reports of progress. This may be report cards, IEP evaluations, regularly scheduled tests, and informal reports from teachers and therapists. All of these should be filed. In addition, school systems may conduct a variety of other assessments. In such instances, you will be asked to sign a written permission form before such testing is conducted. Results of such tests will become part of your child's school records.

You have the right to ask for and get a list of the types of school records kept on your child. The school will give you information on where the records are kept, how you can see them and how you can get a copy of them. There may be a small fee for duplicating these papers. If you would like to see or get a copy of your child's records, you can make a request in writing to the local school district. A sample letter is located at the end of this section.

Q: WHO HAS ACCESS TO THE RECORDS IN YOUR CHILD'S FILES?

A: No one outside your child's school or program has access to your child's records without your written permission. You may notify the school that you do not give permission for anyone outside the system to use these records for any reason. Your rights are based on two federal laws. The first is the Family Education Rights and Privacy Act of 1974. This law applies to the records of all school children. The second law is the Education for All Handicapped Children Act of 1975. This law is also known as Public Law 94-142. In recent years several amendments have been added to this Act, so you may hear people refer to other numbers or names.

Q: WHAT HAPPENS TO YOUR CHILD'S RECORDS ONCE HE/SHE GRADUATES?

A: When a child graduates or finishes public school, all records may be destroyed after a short time. It is very important to have copies of all your child's records before this time. Even after a young person has finished schooling, records may be requested by employers, post-secondary programs or rehabilitation facilities.

Q: ARE THERE WRITTEN POLICIES GUIDING THE ACCESS TO SCHOOL RECORDS?

A: YES!

School systems have written guidelines concerning record keeping and privacy policies. You can request information on policies in your school district if you have any questions or concerns. Most state departments of education also can provide you with this type of information.

3. COMMUNITY SERVICES RECORD KEEPING.

Community services available for children with disabilities can be very supportive of your family's needs. Again, whenever your child participates in a community program, be it at the mental health center or the community pool, keep copies of all reports and records.

It is also very useful to keep a telephone directory of the names and numbers of those people in your community who have been and may continue to be of help to your child and family. Three years from now when your child wants to join the swim team you may need a letter of recommendation from the swim instructor at the pool. In other words, keep that information.

Complete records are helpful in day-to-day contacts with professionals working with your child. You may find it more efficient to keep records in chronological order, with the most recent at the front or on top. That way if your

collection is getting rather large, you have the option of putting earlier files in the attic, basement or under the bed. Files can be housed in a box, in a drawer, or in a file cabinet. Whatever is convenient for you is the best method. When you decide on a convenient system, be sure to keep in mind the amount of material you will be collecting. By the time you keep your own notes and then add all school correspondence and reports, all medical reports, all therapy reports, and records of community activities, this collection may be quite large. Perhaps a separate box or drawer for the records from school, doctors and hospitals and community would be useful. This will allow for expansion and will help to locate records easily.

Q: IS THERE A BEST WAY TO ORGANIZE PAPERS AND RECORDS FOR EASY RETRIEVAL AND ACCESS?

A: Once you begin collecting copies of your child's records, it is important to organize them in a way that the information can be easily retrieved. There is no best way to store information, the important thing is that it works for you. Some parents use loose leaf binders, some use file folders, others store materials in a box or drawer. Whatever system you use, materials are more useful if they are sorted into sections dealing with specific information. For instance, you need a section on Individualized Education Programs, Assessments, Correspondence with school officials, community agencies, and doctors, and on report cards or other reports or communications with teachers. Use a new notebook for each school year to record notes, ideas and conversations. Try to organize it the same way each year.

Be sure to keep your home file current. It can be extremely valuable to you to do this for many reasons. If you move to another school all this information will be necessary to establish a program in the new school. Also, during assessments of your child's progress, the files will provide a history of developmental gains, and losses, and, will help point out any developmental patterns.

Q: ARE THERE RECORDS THAT YOU SHOULD MAKE SURE YOU HAVE IN YOUR HOME FILE?

A: YES! The following list should be helpful as it covers the most important records.

HOME FILE CHECKLIST

- ☐ 1. Birth Certificate
- ☐ 2. Immunization Records
- ☐ 3. Relevant Medical Records
- ☐ 4. School Records
  - ☐ (a) Academic Achievement Reports (tests, report cards, transcripts)
  - ☐ (b) Psychological Evaluations
  - ☐ (c) Physical therapy (PT), Occupational therapy (OT), Speech/Language Evaluations
  - ☐ (d) Current and Past IEP's
  - ☐ (e) Behavioral/Social Evaluations
  - ☐ (f) Vocational Evaluations (interest, skills aptitudes)
- ☐ 5. Samples of child's work and other accomplishments
- ☐ 6. Communication Logs and Correspondence
- ☐ 7. Community Resources
- ☐ 8. Other, as you see the need

No one outside your child's school or program has access to your child's records without your written permission.

SAMPLE LETTER

Dear (fill in the name of the school principal):

I am interested in having copies of my child's school records. (Name of child) is (fill in child's age) and is in (fill in name of teacher's class). Please let me know how and when I can get copies of this information for my home files.

Please write to me at:
(your address)_____

_____

_____

or phone on (give daytime number).

Thank you.

Sincerely yours,

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